DOCUMENT RESUME

ED 353 735 EC 301 766

AUTHOR	Taylor, Steven J.; And Others
TITLE	Permanency Planning for Children with Developmental Disabilities in Pennsylvania: The Lessons of Project Star [and] Executive Summary.
INSTITUTION	Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	92
CONTRACT	H133B00003-90
NOTE	82p.
PUB TYPE	Reports - Evaluative/Feasibility (142)
EDRS PRICE	MF01/PC04 Plus Postage.
DESCRIPTORS	Adopted Children; *Adoption; Children; Child Welfare; *Developmental Disabilities; Disabilities; Family Relationship; Long Range Planning; Placement; *Policy Formation; Program Development; Program Implementation; *Public Policy; Social Services
IDENTIFIERS	Pennsylvania (Pittsburgh); *Permanency Planning (Foster Care); *Project STAR PA

ABSTRACT

This report examines "permanency planning" and "special needs adoption" for children with disabilities, based on the experience of Project STAR in Pittsburgh, Pennsylvania. Project STAR (Specialized Training for Adoption Readiness) was established in 1985 to provide support services for families of children with disabilities and to locate alternative family placement for children who cannot live with their birth families. Project STAR's adoption services fall into five categories: permanency assessment and preparation of child; family recruitment and preparation; family and child preplacement/placement; post-placement services; and post-finalization services. Factors accounting for the success of Project STAR's adoption efforts are outlined, such as offering support services responsive to the needs of adoptive families. Project STAR's permanency planning activities attempt to build or strengthen permanent and stable family relationships for children, and involve family preservation, family involvement with their children placed out of home, family reunification, and finding other permanent options. The policy context of children and youth services and mental health/mental retardation services in Pennsylvania is discussed. Policy issues that impact specifically on Project STAR's mission are then examined, and recommendations are offered. An appendix describes the methodology used in the policy analysis, and an executive summary is provided as a separate document. (JDD)

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PERMANENCY PLANNING FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES IN PENNSYLVANIA: THE LESSONS OF PROJECT STAR

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PERMANENCY PLANNING FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES IN PENNSYLVANIA: THE LESSONS OF PROJECT STAR

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Preparation of this report was supported by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education for the Research and Training Center on Community Integration through Cooperative Agreement #H133B00003-90 awarded to the Center on Human Policy at Syracuse University. The opinions expressed herein are solely those of the authors and no endorsement by the U.S. Department of Education should be inferred.

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INTRODUCTION

This report examines the lessons for state and county policy on "permanency planning" and "special needs adoption" for children with disabilities based on the experience of Project STAR in Pittsburgh, Pennsylvania.

The fields of mental retardation and disabilities, generally, continue to witness an evolution in the design of community services for adults and children. Until recently, most states focused their attention on deinstitutionalization--the movement of people with disabilities from large public institutions to community-based programs. In Pennsylvania, as in most states, the populations of public institutions have declined at a steady pace as resources have been shifted to support people with developmental and other disabilities in group homes, community living arrangements, and other community settings.

While deinstitutionalization dominated the attention of the fields of developmental disabilities and mental health throughout the 1970s and most of the 1980s, the 1990s are characterized by a new emphasis on the quality of life and community participation. Recent years have seen the emergence of new approaches to supporting adults and children with disabilities in the community. For children with disabilities, there is a growing recognition that every child needs a permanent and stable home and family. In line with this, a new priority has been placed on family support services and alternative family placement for children who cannot live with their birth families.

Viewed in the context of current national trends, Project STAR stands at the forefront of agency efforts to insure children's right to permanent and stable family relationships. Project STAR has demonstrated that children with a range of disabilities can be supported in their birth families or placed in adoptive families.

In this report, we examine the experience of Project STAR for the lessons for state and county policy toward children with mental retardation and other disabilities in Pennsylvania[1]. The report is divided into three major parts. Part I reviews the history and experience of Project STAR. Part II examines the policy context in which Project STAR operates. Part III addresses policy issues that have an impact on Project STAR's mission and contains policy recommendations based on this review. An Appendix describes the methodology on which this policy analysis is based.

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[1] This report is directed primarily toward Pennsylvania's mental retardation and service system. Project STAR was founded to serve children with developmental disabilities and continues to focus on this population. Since Project STAR has also served children with emotional disturbance and since issues in mental retardation and mental health often overlap in Pennsylvania, we make reference to both the mental retardation and mental health systems in this report. However, most of the data collected for this report relate specifically to the mental retardation system.

PART I. PROJECT STAR:

FROM ADOPTION TO PERMANENCY PLANNING

Project STAR was established in 1985 with funding from the Pennsylvania Developmental Disabilities Planning Council (DDPC) as a collaborative project of The Rehabilitation Institute of Pittsburgh, the Allegheny County Children and Youth Services agency, and Three Rivers Adoption Council (TRAC). Project STAR was administratively housed at The Rehabilitation Institute and is currently a program of that organization.

Project STAR was one of four projects funded by the DDPC under its "Adoptive Family Recruitment Objective" for a three-year funding period. The project's budget for the three years included $176,640 in DDPC funds and $63,042.50 in matching funds from the collaborating agencies. The other projects funded by DDPC were the National Adoption Center, Project Concern, and Tabor Children's Services. According to an evaluation of these projects conducted by the National Resource Center for Special Needs Adoption (Brown & Lakin, 1989), a total of 79 children were placed in adoptive families through these four projects. Project STAR accounted for 39 of these placements.

Since 1988, when this three-year funding from DDPC ended, Project STAR has been funded through a patchwork of grants, contracts, and other sources:

*DDPC approved "bridge funding" of $75,000 to continue support for an additional year. Subsequently DDPC awarded Project STAR a $71,200 15-month grant in 1989 for a permanency planning project to demonstrate the impact of collaboration techniques on effecting adoption. A competitive two-year "Family Permanency and Supports" grant was awarded by DDPC for

$70,000 for a Beaver County office to investigate the use of existing community resources for the recruitment of families for children with developmental disabilities.

*With the support of Allegheny County Commissioner Tom Foerster's office, Project STAR received a Human Services Development Fund grant through the Allegheny County Children and Youth Services (CYS) agency.

*Commissioner Foerster's office also assisted Project STAR in receiving a three-year ($50,000, $40,000, and $30,000) grant from the Richard King Mellon Foundation.

*Since 1989, the Pennsylvania Offices of Children, Youth, and Families, Mental Retardation, and Mental Health have also provided direct funding to Project STAR. During the past fiscal year, the Offices of Children, Youth, and Families and Mental Health both contributed $20,000 and Mental Retardation contributed $42,000.

*TRAC arranged for Project STAR to receive United Way funding for a family recruiter located at TRAC.

*Project STAR has received grants from the Forbes Fund and a recent three-year $69,800 per year grant from the Children's Trust Fund.

*Project STAR was recently awarded a two-year $75,000 per year federal grant for post-adoption support services.

*Project STAR receives $60,000 per year from "One Church/One Child" for adoption services for black children.

In addition to these grants and contracts, a major funding source for Project STAR is direct purchase of service contracts from county children and youth services

agencies for adoption services. Project STAR has contracts with Allegheny, Armstrong, Beaver, Butler, Erie, and Westmoreland counties and anticipates $70,000 in funding from these contracts during the current year. The Allegheny County Office of Mental Retardation has also contracted with Project STAR for "Personal Futures Planning" for a young man living in a community living arrangement.

Mission of Project STAR

Consistent with its initial funding from DDPC, Project STAR was founded as an adoption agency for children with developmental disabilities. Project "S.T.A.R." stood for "Specialized Training for Adoption Readiness." During its first three years, the project focused on identifying children available for adoption, recruiting, screening, and training prospective adoptive parents, and supporting the adoption.

Beginning in 1989, Project STAR's mission gradually broadened to focus on permanency planning for children with disabilities. As noted in the evaluation of the DDPC's four adoption agencies by the National Resource Center for Special Needs Adoption, these projects placed 30 children under three years of age suggesting a weakness in family support services for families with young children. This evaluation recommended:

> All the systems offering placement and supervision of children in placement should collaborate in an effort to integrate permanency planning values and practice at all points on the continuum (beginning with family support to maintain the child in his birth family, release counseling when appropriate, reunification of child with birth or extended family, and finally, adoption recruitment, assessment and training) (Lakin & Brown, 1989).

From its start, Project STAR had prided itself on being a "children's service,"

rather than a service for adoptive parents; the children and not the prospective adoptive parents were viewed as the agency's "clients." The adoption of permanency planning as a mission was a logical extension of this focus.

Permanency planning is both a planning process and philosophy directed toward ensuring each child's rights to a permanent home and stable relationships with one or more adults (Center on Human Policy, 1987; Taylor, Lakin, & Hill, 1989). According to the philosophy of permanency planning, children belong in families and need permanent family relationships. Permanency planning emphasizes supports to families to enable them to care for their children, family reunification when children have been placed out-of-home, and adoption or other permanent family placements for children who cannot live with their birth families.

In child welfare, or children and youth services, permanency planning is required by the federal Adoption Assistance and Child Welfare Act of 1980, P.L. 96-272. The requirements of P.L. 96-272 include the development of a "case plan" and a "case review system" for children in foster care or child care institutions. The case plan is defined as "a plan for assuring that the child receives proper care and that services are provided to the parents, child, and foster parents in order to improve the conditions in the parents' home, facilitate return of the child to his own home or the permanent placement of the child, and address the needs of the child while in foster care." The case review system includes at least two reviews: (1) a 6-month review by a court or administrative body of the appropriateness of the placement, progress toward addressing the reasons for the placement, and a projected date by which the child can return home or be placed for adoption; and (b) an 18-month "dispositional hearing" (and periodically thereafter) by a court or court-approved administrative body

on the child's future status, including return to the parent, continued foster care placement, adoption, or permanent foster care. In Pennsylvania, county children and youth services agencies are bound by the requirements of P.L. 96-272 for all children in their custody.

Few mental retardation, developmental disability, or other disability agencies in the United States have incorporated permanency planning into their policies and procedures. The State of Michigan is a notable exception and this state's experience is examined later in this report.

As Project STAR's mission has broadened from adoption to permanency planning, it has encountered new and formidable challenges.

Project STAR: Adoption

Project STAR has been extremely successful in arranging adoptions and has demonstrated that caring and loving adoptive families can be found for children who have been considered "unadoptable" because of their disabilities. Since its establishment, Project STAR has placed children with severe multiple disabilities, autism, emotional disturbance, profound mental retardation, and severe medical involvements in adoptive families.

From 1985 until the present, Project STAR has placed 80 children with disabilities in adoptive families. Among these placements, there have been few "disruptions," or failed placements. Depending on how figures are calculated, disruptions range from three to ten. Project STAR was not involved in post-placement services for six of these children. Project STAR's figures compare extremely favorably with the general rate of disruptions of special needs adoptions (although it can be argued that the disruption rate might increase over time, since most adoptions are

relatively recent). A report conducted by the Education Law Center in 1987 indicated that an increasing number of special needs adoptions were failing in Pennsylvania. The report cited estimates from some county children and youth services directors that from 25% to 50% of adoptions in their counties failed.

Project STAR's adoption services fall into five broad categories: (1) Permanency Assessment and Preparation of Child; (2) Family Recruitment and Preparation; (3) Family and Child Preplacement/Placement; (4) Post Placement Services; and (5) Post Finalization Services. FIGURE 1 details each of these services. A number of factors account for the success of Project STAR's adoption efforts. First of all, staff members share a common commitment to the philosophy that all children belong in families. A child's disability is not viewed as a barrier to adoption. Some agencies might give up on finding adoptive families for some children with disabilities; Project STAR does not.

Second, Project STAR carefully matches families and children. Staff members get to know both the families and the children well, and placements take into account the needs and circumstances of both. Project STAR provides families with positive, but accurate descriptions of prospective children, including social, educational, medical, and developmental information. "Lifebooks" or recruitment albums are sometimes prepared that contain color photos of children and discuss their personalities and individual characteristics as well as their disabilities. Videotapes and pictures are often used to give families a clear picture of prospective children. Of course, families and children also have the opportunity to meet prior to the placement.

Third, in contrast to many adoption agencies, Project STAR is open to families who do not fit the traditional mold. The project looks for families who are caring, loving, and capable of raising a child who happens to have special needs. Within

FIGURE I.
PROJECT STAR ADOPTION SERVICES

Permanency Assessment of Child — 25 - 60 hours

- Two to three child interviews
- Three to five observations of child in various settings
- Research and summarize all available records on the child
- Begin collecting all needed data to obtain maximum adoption assistance
- Interviews of past/present caretakers
- Interviews of collaterals (teachers, physicians, caseworkers, etc.)
- Photographs/videos of child to use in child specific recruitment and matching
- Consult/initiate "Lifebook"
- Refer for additional evaluations as needed
- Prepare the Permanency Assessment Report (summarizes all the above and contains recommendations for meeting the full range of the child's needs)

Family Preparation (Home Study) — 35 - 60 hours

- Two to three individual interviews and eight (weekly) group sessions
- Interviews of potential siblings
- Analyze family's strength/history/motivation/personal and community resources and prepare written Family Summary (Home Study)
- Three to four "Matching Meetings" where family explores possible children for placement (views photos, videos, reads summary records, etc.)

Family and Child Preplacement/Placement — 25 - 50 hours

- Written and verbal "presentation" of child's information to family
- Preparation for adoptive placement (Lifebook, Futures Planning, etc.)
- Produce picture album, video, and/or cassette tape of family to prepare child for move
- Observation and first visit between family and child
- Arrange multiple visits between family and child
- Supervise and evaluate potential for successful adoptive placement
- Preparation and counseling with the child during preplacement visits
- Finalize arrangements for all adoption assistance benefits, school placement and auxiliary supports (i.e., therapy)

Post Placement Services — 35 - 65 hours

- Phone and face-to-face supervision of family and child
- Support family to make contacts with resources for the child
- As needed, support child/family with in-home services
- Assist family in connecting to home community parent support groups, etc.
- Host quarterly gatherings and distribute newsletter of Project STAR families to link experienced with new adoptive families
- Arrange and participate in all proceedings related to legalization of the final adoption

Post Finalization Services — Hours as needed

- With the exception of formal supervision, all the above post placement services are provided depending upon family's and child's needs or requests

these qualifications, Project STAR will work with families who would be rejected by most adoption agencies. These include single parents, people with disabilities, and families from lower socio-economic backgrounds. The project has also worked hard to recruit African-American families. Many families interviewed or surveyed in this review reported that they had been turned down by other adoption agencies. One single parent compared her experiences with Project STAR and other adoption agencies:

> You can't expect to compete with a 2 parent family. However, it is extremely discouraging. I felt like an outcast. In this day and age divorce is a fact of life and I have known 2 parent families adopting a child and later divorcing. There should be open communication for the single parent, not a cut and dried response of "No!" I tried for 2 years before anyone would even consider me as an adoptive parent, and Project STAR accepted me. My feeling is that it's better to be loved by one parent than by no parent.

A parent with a disability had this to say about Project STAR in comparison with other adoption agencies: "They're the only people I know of who will deal with people with disabilities."

Fourth, <u>according to most adoptive parents interviewed or surveyed, Project STAR staff members are personal, friendly, and caring</u>. In general, the adoption process is often frustrating for families and characterized by unanticipated delays, legal obstacles, and excessive paperwork. For most families, Project STAR helps make the process less impersonal and more bearable. One parent said, "They were the kindest people to deal with." Families' experiences with other private or public agencies varied from satisfaction to extreme dissatisfaction, but the caring and personal nature of

Project STAR was the most frequently cited difference between this agency and others. This characteristic of Project STAR is so important to families that some worried that this would be lost if the agency expanded. As one parent stated, "I hope they don't become so big or impersonal that they just process requests and lose that personal, sensitive awareness of the individual--that is so important to someone who wants to open their hearts and home to a child."

Fifth, in addition to Project STAR's personal touch, the agency's services seem generally responsive to the needs of adoptive families. Project STAR makes a long-term commitment to families and their children, and parents know that they can call on the agency for support. All of the families interviewed or surveyed in this review evaluated Project STAR positively. Many cited parent support groups or parent-to-parent contacts made through Project STAR as important. Some found the agency helpful in providing information or arranging for services, although some said they usually did things by themselves. Families reported differing opinions about the effectiveness of training sessions. Some found the pre-placement training extremely useful, including one mother who added that she complained about it at the time. Several who had previous knowledge of disability issues and services found the training to be less useful. When families reported dissatisfaction with Project STAR's services, this generally reflected idiosyncratic factors; for example, a particular staff member who had since left the agency or, in one case, an experience unrelated to the adoptive child. In the structured survey completed by 11 families, the following comments summarize their overall evaluation of Project STAR:

"Very professional, efficient, willing to help."

"Excellent, good preparation and support."

"Very professional, personal, 100% satisfaction, 100% backup."

"Excellent, offer lots of things to help parents."

"Nicer when first started, so many people there now."

"Good--they've given what we needed when we needed it."

"Excellent--staff well educated."

"While I was going thru the adoption process they were going thru a real transition and staff turnover."

"Excellent--friendly and caring."

"Above average."

"The people make the agency--warm, concerned, caring, they don't push anything on you, care about what you say and how you feel, you are treated as an individual."

Finally, Project STAR maintains the delicate balance between being child-centered and sensitive to adoptive families. Unlike most adoption agencies, Project STAR is not a "child-find" service for families and does not charge them a fee for adoption services. Therefore, staff members can focus on finding the best family for each child.

While Project STAR adopts a child-centered focus, it also seeks to meet the needs and preferences of adoptive families. Several members of its staff are adoptive parents themselves and empathize with their experiences. For their part, adoptive families appreciate both the fact that they do not have to pay for Project STAR's services and its commitment to the children themselves.

As part of this review, we visited the homes of eight adoptive families. The families varied widely in their racial and cultural background, socio-economic status,

family type (one versus two-parent), and other characteristics. What these families seemed to share in common, however, was their love for their children. We were impressed by the depth of their commitment and caring. One mother stated, "I feel like I birthed them myself." Another said, "Except for the labor pains, he's always been with us." This is a tribute to the families and to Project STAR.

Project STAR: Permanency Planning

Project STAR now defines itself as "Permanency Planning Advocates of Western Pennsylvania." This phrase has recently replaced "Specialized Training for Adoption Readiness" on Project STAR's letterhead. When Project STAR describes itself as "permanency planning advocates," it is not referring to the procedural requirements mandated by P.L. 96-272. Project STAR does not have custody of any children; county children and youth services agencies undertake the case plan and case review procedures required by the law. For Project STAR, permanency planning is both a philosophy and a set of practices designed to encourage permanency in children's lives.

As a philosophy, permanency planning increasingly guides all of Project STAR's activities. Unlike many adoption agencies, Project STAR seems to ask, "How can we build or strengthen permanent and stable family relationships for the child?," as opposed to asking, "How can we find children for adoptive families (or vice versa)?" The initial step in the adoption process is a "Permanency Assessment" of the child. There is a subtle, but important difference between a "Child Assessment," on the one hand, and a "Permanency Assessment," on the other. A "Child Assessment" focuses on the characteristics of the child; a "Permanency Assessment" looks at both the child's characteristics and existing social relationships and explores a full range of

permanency options, including but not limited to adoption. In some cases, Project STAR has advocated for permanent foster care for children living with caring foster families unable to adopt them, as opposed to severing the relationships by recruiting adoptive families.

As a set of practices, permanency planning at Project STAR refers to a range of services as well as planning and advocacy efforts to achieve permanency for children living out-of-home or at risk of placement. Project STAR's first permanency planning efforts were supported by a DDPC grant in 1989; today these efforts are funded by different grants. County children and youth services agencies do not contract with Project STAR for permanency planning, since this is viewed as their responsibility. The agency's permanency planning activities fall into four categories.

The first is "family preservation" or efforts to prevent out-of-home placement. Depending on the family's needs and circumstances, these efforts take many forms: planning and coordination of family support services; advocacy for the family with human services agencies; direct provision of goods or services; and information, encouragement, and emotional support to families. We accompanied one staff member to the home of a new-born with severe disabilities and medical involvements. The parents were pessimistic about the infant's future and were considering placement in a private institution; the father, in particular, rejected the child. The Project STAR staff member talked honestly, but sympathetically with the parents. She explained that their image of their child's future was inaccurate and gave examples of similar children who are living and thriving in families. While she encouraged them to try to maintain their child at home, she asked them to consider adoption, rather than institutional placement. The family placed the child in foster care for four months, but then as a

consequence of Project STAR's intervention, decided to try to raise their child themselves. Nearly one year later, the child is still living with the family.

The second category of permanency planning activities relates to encouraging a family's involvement with their children who have been placed out-of-home. For a host of reasons, families may place their children in institutions, community living arrangements, or in foster homes. In the field of developmental disabilities, out-of-home placement often has signalled an end to the family's relationship with a child.

Project STAR has worked closely with some birth families to encourage and facilitate their continued relationship with their children. In the case of one single mother whose daughter requires nursing care, Project STAR supported the mother's decision to place the child in a foster home arranged through the county MH/MR agency. Project STAR offered steady encouragement to the mother to keep up contact with her daughter, advocated for the mother with human service agencies, and worked to facilitate cooperation and open communication between the mother and the foster mother.

The third category is "family reunification." As suggested above, placement in the field of developmental disabilities traditionally has been viewed as a terminal event. Once placed, the child was never expected to return home. For the vast majority of children with developmental disabilities who are placed out-of-home, the first option should be reunification with their families. Project STAR has not only encouraged family reunification, but helped arrange support services to enable children to return to their families.

The final category of Project STAR's permanency planning activities relates to finding other permanent options for children who cannot or should not be reunited with their families. For children whose ties with their families have been broken, adoption is the option of choice. Few children in the mental health and mental retardation systems are legally free for adoption, however. Even when families are no longer involved with children in private institutions and other placements in the mental health and mental retardation systems, parental rights have seldom been terminated and children are left in a legal limbo. Permanent foster care is likely to be the most stable and permanent option for these children.

In contrast to Project STAR's adoption placements, it is difficult to cite statistics on the effectiveness of its permanency planning efforts. Many policy and legal barriers stand in the way of permanency for children with disabilities, and especially those in the mental health and mental retardation systems. For example, in one instance, a child was placed in a foster home and his birth mother was willing to relinquish parental rights. Since he was placed voluntarily into the mental retardation system, however, the county children and youth services agency has avoided responsibility for assisting in termination of rights and adoption.

Through its permanency planning activities, Project STAR is currently working with six children. Of these children, Project STAR is attempting to preserve or reunite the families in four cases and pursing adoption, or if parent rights cannot be terminated, permanent foster care in two cases.

PART II. THE POLICY CONTEXT

Before we address the issues that have an impact on Project STAR and special needs adoption and permanency planning generally, it is important to examine the policy context of children and youth services and mental health/mental retardation services in Pennsylvania. Specific issues cannot be understood apart from this policy context.

CYS Versus MH/MR Services

Like many states, Pennsylvania supports both "generic" children and youth services and "categorical" mental health/mental retardation services. Children with emotional disturbance, mental retardation, or developmental disabilities may be placed out-of-home either through children and youth services or mental health/mental retardation agencies.

County and youth services agencies are designed to serve abused, neglected, or abandoned children, including those with disabilities. As noted previously, these agencies are required to comply with the permanency planning procedures mandated in P.L. 96-272, including the "case plan" and "case review system" requirements. Pennsylvania Department of Public Welfare (DPW) regulations require county children and youth services agencies to evaluate the adoptability of children in placement and to provide or arrange for adoption services. The General Assembly recently increased the reimbursement rate for adoption services from 80% to 100%. According to a 1991 report by the Legislative Budget and Finance Committee, 16,737 children were placed out-of-home by these agencies in 1990; 2,040 of these children had a goal of adoption and 1,101 were legally freed for adoption (the Pennsylvania State Association of County Commissioners [PSSACC] and Children and Youth Administrators [PCYA]

believe that these latter figures overestimate the number of children waiting for adoption).

As in most states, Pennsylvania's county children and youth services agencies are generally regarded as overburdened; crisis intervention takes priority over permanency planning and adoption. A Proposal for a Statewide Adoption System states:

> . . .the vast majority of the limited resources that are available to serve dependent children and their families are being used to protect children who are in immediate danger of experiencing serious harm. . .The goal for these children is adoption but the crisis emphasis of the system in which these children are served makes realizing the goal unlikely at best.

State and county administrators interviewed for this review generally agreed with this assessment, although there is no consensus regarding the solutions to the problems in this system.

In contrast to children and youth services agencies, Pennsylvania mental health/mental retardation agencies traditionally have not been involved in permanency planning and adoption. In the field of child welfare, permanency planning is a widely known and commonly accepted philosophy; in the fields of mental health and developmental disabilities, it is almost unheard of. It is a cultural expectation that children should grow up in families, but this expectation has been waived for children with disabilities. For these children, out-of-home placement has been viewed as a service option and not as family abandonment. Presumably, if the parental rights of families of children served by mental health/mental retardation agencies have

been terminated, which is rare, children and youth services agencies would take over custody and adoption would be a possibility.

The DPW's Office of Mental Health (OMH) and Office of Mental Retardation (OMR) have begun to devote attention to permanency planning and adoption. The following efforts are noteworthy:

1. The Child and Adolescent Services System Program (CASSP) of the Office of Mental Health is designed to coordinate services for children and adolescents in need of multiple services and emphasizes permanency for these children.

2. The Office of Mental Retardation's 2176 Medicaid waiver includes permanency planning as a reimbursable service. To our knowledge, Pennsylvania is the only state to explicitly include permanency planning in its Medicaid waiver program.

According to Office of Mental Retardation documents, in 1991, there were 707 children with mental retardation under the age of 18 living in mental retardation facilities and other out-of-home placements. These included 387 children in Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), 310 children in licensed community and family homes, and 10 older children in state centers or MR units. TABLE 1 contains a breakdown of children placed out-of-home in the mental retardation system. During Fiscal Year 1990-91, 229 children were admitted to out-of-home placements, including 159 children placed in ICFs/MR. TABLE 2 summarized these figures.

State Versus County

In both children and youth services and mental health/mental retardation services, Pennsylvania ostensibly supports a county-based service system. The DPW funds and regulates services; county children and youth services agencies and mental

TABLE 1

CHILDREN PLACED OUT OF HOME IN THE MENTAL RETARDATION SYSTEM

Persons Under the Age of 18 in Residence as of July 1, 1991

ICF/MR

State Centers/MR Units	10
Private ICFs/MR*	387

COMMUNITY RESIDENTIAL

	Size			
Living Arrangement	1 - 3	4 - 8	9 - 16	17+
Supervised Living	91	44	3	125
Semi-Independent	1			
Family Living	44	2		
Home-Based	15	6		

*includes large and small facilities

TABLE 2

ADMISSIONS OF CHILDREN IN THE MENTAL RETARDATION SYSTEM

Admissions of Persons Under the Age of 18 for Fiscal Year 1990-91

ICF/MR

State Centers/MR Units	5
Private ICFs/MR*	159

COMMUNITY RESIDENTIAL

	Size			
Living Arrangement	1 - 3	4 - 8	9 - 16	17+
Supervised Living	24	14	2	12
Semi-Independent				
Family Living	13			
Home-Based	15	4		

*includes large and small facilities

health/mental retardation agencies provide or arrange for services. Of course, Pennsylvania continues to operate state centers or institutions, directly. These centers remain outside of county control. To the credit of the Office of Mental Retardation, only 10 children under 18 years of age live at state centers or MR units.

While Pennsylvania has adopted a county-based service system for children and youth services and mental health/mental retardation services, large (over eight beds) private ICFs/MR operate independently of county mental health/mental retardation agencies. These facilities are funded by federal and state Medicaid dollars and are regulated by the state, but appear to function as relatively autonomous entities within the mental retardation system. This not only undermines county control and responsibility, but poses a major barrier to permanency for the 387 children placed at these facilities.

Both children and youth services and mental health/mental retardation services in Pennsylvania have the same strengths and weaknesses found in any county-based service system. As strengths, county-based systems are more responsive to local needs and circumstances and allow for greater flexibility and innovation than centralized systems. As a weakness, the quality and responsiveness of services can vary widely from county to county. For example, the 1991 Legislative Budget and Finance Committee evaluation of special needs adoption documented dramatic differences in counties' interpretations and implementations of adoption assistance subsidy regulations and in the amount of subsidies provided to adoptive families.

As in other states with county-based service systems, in Pennsylvania, there appears to be a "creative tension" between county and state governments. Counties may feel burdened by state mandates and underfunded to meet them; the state may

feel that its policy initiatives are undermined by county recalcitrance. In most states, the truth lies somewhere between these extreme positions.

Strengths

Like many previous reports on family support services, adoption, and permanency planning in Pennsylvania, this report will identify policy issues and barriers that have on impact on children with disabilities. While problems must be identified before solutions can be implemented, an overemphasis on barriers and issues can lead to a sense of powerlessness and hopelessness--a sense that nothing makes a difference. Pennsylvania will never develop a perfect children and youth services or mental health/mental retardation service system; no state will. In attempting to enhance permanency for children with disabilities, leaders in Pennsylvania should recognize and build on their strengths. In the course of this review, several strengths became apparent.

On both the county and state levels, many officials and agency representatives have sought to learn from the experience of Project STAR and have made changes in services based on this experience. This no doubt reflects the effectiveness of Project STAR and persuasiveness of its director. As a state agency representative said, "Everyone agrees it is an excellent program and is really producing." This also reflects the openness of state and county officials and others to take seriously Project STAR's message.

Compared with the vast majority of state agencies, Pennsylvania mental health, mental retardation, and developmental disability agency officials are knowledgeable about and committed to the philosophy of permanency planning. The Developmental Disabilities Planning Council (DDPC), which has a national reputation for its support

and promotion of innovative efforts, has funded several adoption and permanency planning initiatives, in addition to statewide evaluations. The Office of Mental Health is attempting to incorporate permanency planning into the CASSP Program. The Office of Mental Retardation not only included permanency planning in its Medicaid 2176 waiver, but sponsored a training initiative on "Permanent Families: Permanent Homes." Through memoranda to county agencies and directives to regional program managers, OMR has also discouraged placements of children with mental retardation in state centers and private institutions.

Addressing the issues from the vantage point of children and youth services, many Pennsylvania statewide associations, including the Permanency Planning Task Force, the Pennsylvania Council of Children's Services, One Church One Child, and county associations, have attempted to address the barriers to adoption and permanency for children with special needs. The Legislative Budget and Finance Committee has devoted significant attention to adoption and permanency planning.

As a tangible indicator of their support for special needs adoption and permanency planning, many public agencies have funded Project STAR or recommended funding by private agencies. DDPC has underwritten Project STAR's efforts through several grants. The Allegheny County Commissioners, and specifically Chairman Tom Foerster's office, have been strong advocates of Project STAR in seeking public and private funding. Within the Department of Public Welfare, the Offices of Mental Health, Mental Retardation, and Children, Youth and Families have provided direct funding to Project STAR, even though this is outside of their usual realm of operation. DPW's Office of Policy, Evaluation and Development has been an advocate for Project STAR within the Department.

Pennsylvania can be faulted for lacking stable funding mechanisms for innovative adoption and permanency planning programs like Project STAR. This hardly makes it unique among the states. At least in Pennsylvania, the funding has been patched together. Project STAR simply would not exist in most states.

PART III. POLICY ISSUES AND RECOMMENDATIONS

This report specifically examines the policy issues that impact on Project STAR's adoption and permanency planning mission for children with developmental disabilities. Of course, Project STAR's mission is affected by issues confronting special needs adoption and mental retardation services in general.

Previous evaluation reports conducted by the National Resource Center for Special Needs Adoption (Brown & Lakin, 1989), The Education Law Center, Inc. (1987), Human Services Research Institute (1991), and the Legislative Budget and Finance Committee (1991) document barriers to adoption and permanency planning in Pennsylvania. While this policy review did not look in depth at all of the issues addressed in these evaluations, our findings are consistent with many of those contained in these previous evaluations:

1. **Pennsylvania needs a stable funding source for flexible and individualized family support services for families of children with disabilities**. Permanency planning requires that family support services be available to enable children to remain with their families (see Center on Human Policy, 1987). The Human Services Research Institute has recommended the enactment of Family Support Legislation in Pennsylvania and this recommendation should receive careful consideration.

2. **For children in the custody of children and youth services agencies, increased attention must be devoted to adoption and permanency planning**. Evaluations have consistently documented barriers to adoption and permanency planning for children in the custody of county children and youth services agencies. A broad range of associations, agencies, and groups, including the Legislative Budget

and Finance Committee, the Permanency Planning Task Force, the Pennsylvania State Association of County Commissioners, the Pennsylvania Children and Youth Administrators, the Pennsylvania Council of Children's Services, and the Department of Public Welfare, agree that major changes are necessary to eliminate the barriers to adoption and permanency planning. Some of these groups have supported one of the several proposals for a "statewide adoption system"; others, notably, associations of county officials, have expressed their opposition to all statewide adoption proposals and recommended changes in state policy, regulations, and funding mechanisms. While there is no consensus on the issue of a statewide adoption system, some statewide non-county, non-profit system will be put into place in Pennsylvania. In March, 1992, DPW issued a "Request for Proposal" for a Pennsylvania Statewide Adoption System. This should not be viewed as a substitute for other needed changes in Pennsylvania's mental health, mental retardation, and children and youth services systems.

3. **Adoption assistance subsidies are inadequate and provided in an inequitable manner**. The Legislative Budget and Finance Committee's evaluation documented wide variations in counties' administration of adoption subsidies. Counties vary widely in the amounts of subsidies provided to adoptive families and their interpretations of federal and state requirements (e.g., means test for adoptive families). Further, on a statewide basis, adoption subsidies are significantly lower than foster care rates. Regulatory and policy changes are necessary to insure adoption subsidies are adequate and provided equitably.

4. **Post-adoption services are inadequate**. Virtually all evaluation reports on special needs adoption in Pennsylvania and major statewide groups agree that

post-adoption services have been inadequate. As recommended in these reports and by these groups, these services need to be expanded to support families in caring for their adoptive children.

In addition to these issues, which have an impact generally on adoption and permanency planning, this policy review identified a number of additional barriers that must be addressed to insure permanency for children with developmental disabilities in Pennsylvania. These are addressed separately for the children and youth services and mental retardation systems.

Children and Youth Services

"Special needs adoption," including adoption for children with mental or developmental disabilities, has received considerable attention in Pennsylvania. As described above, many agencies and associations--DPW's Office of Children, Youth and Families, the Legislative Budget and Finance Committee, the Permanency Planning Task Force, the State Associations of County Commissioners and Children and Youth Administrators, the Pennsylvania Council of Children's Services and others--have identified barriers to adoption in Pennsylvania and have recommended major reforms in the current children and youth services system. Recommendations range from the implementation of a statewide adoption program, on the one hand, to increased funding and elimination of state imposed obstacles in support of county administered services, on the other. Despite a lack of consensus on the solutions to problems in the current system, a statewide adoption program is imminent. In addition, with the support of practically all interested agencies and associations, the General Assembly recently approved a reimbursement rate of 100% for county adoption services.

While the increased attention focused on adoption of children with special needs in Pennsylvania is necessary and commendable, adoption should not be considered apart from the broader issue of permanency for children in the custody of children and youth services agencies. Adoption is only one permanency option, and an over-emphasis on adoption to the exclusion of other options will not serve the interests of many children in the CYS system. As stated by the State Associations of County Commissioners and Children and Youth Administrators (1991) in their response to statewide adoption proposals, ". . .the priority for permanence, by federal and state law and regulations, must be to consider all options: return home, place with extended family, adoption, long term care foster care, independent living. . .Adoption is only one component of permanency." Whether or not an overemphasis on adoption at the expense of other options is inherent in the proposed statewide system, this point is valid and should be taken into account in any reforms of the current system.

First of all, for many children in the CYS system, adoption is neither a goal nor a realistic possibility at this time. According to the report of the Legislative Budget and Finance Committee, in 1990, 16,737 children were in placement in the CYS system; only 2,040 (12.2%) had a goal of adoption and only 1,101 were legally freed for adoption. Both proposals for a statewide adoption system and recommendations made by the State Associations of County Commissioners and Children and Youth Administrators (1991) would affect a relatively small number of children in placement.

Further, just as adoption is not a priority in the county CYS agencies, neither are other permanent options. As suggested previously, CYS agencies have a crisis emphasis; their resources "are being used to protect children who are in immediate danger of experiencing serious harm."

Permanency planning is both a planning process and a philosophy. As a planning process in Pennsylvania, it is the responsibility of county CYS agencies to provide for a case plan and a case review system. This does not mean that county CYS agencies have the resources or orientation to implement the philosophy of permanency planning. The experience of Project STAR is instructive in this regard.

Project STAR has been funded by a range of grants from public and private agencies and contracts with county agencies. Since its establishment, at least six county CYS agencies have contracted with Project STAR for adoption services, but a county CYS agency has never contracted with Project STAR for any other permanency planning services. Yet, as its grant-funded permanency planning projects demonstrate, Project STAR has the experience and capacity to pursue other permanent options for children, including family preservation and reunification and long-term foster care.

Finally, even for those children who have a goal of adoption, adoption may not be a desirable or realistic possibility. Some of these children may never be freed for adoption; others, especially older children, may either not want to be adopted or may already be living in caring and permanent situations. Project STAR's experience indicates that some children may be living in loving long-term foster families who are unable to adopt because of financial disincentives and other reasons; it would be tragic to break up a foster family situation that is as loving and permanent as any adoptive family.

Based on this policy review, we offer the following recommendations for Pennsylvania's children and youth services system.

Recommendation 1. Reform proposals for Pennsylvania's children and youth services system should address permanency for children with disabilities as opposed to an exclusive emphasis on adoption.

Whether put forth by state, county, or private groups, the reform proposals for Pennsylvania's special needs adoption system are framed in terms of "permanency planning," but the specifics of the proposals focus narrowly on adoption. Adoption is the option of choice for many, but not all children. An over-emphasis on adoption may result not only in the needs of many children being ignored, but also in the neglect of other permanent options most suitable for specific children.

Recommendation 1.A. Any statewide system should support the creation of permanent family outcomes for children and not adoption as the single option.

The proposed statewide system has advantages and disadvantages. The advantages have been identified and documented by the Department of Public Welfare, the Permanency Planning Task Force, the Pennsylvania Council of Children's Services, and the Legislative Finance and Budget Committee, among others. The disadvantages have been articulated by the State Associations of County Commissioners and Children and Youth Administrators; these associations have recommended many other reforms worthy of consideration (e.g., expansion of the One Church One Child initiative). DPW's October 1991 proposal seems to take into account many of the county associations' criticisms; however, this proposal does not address concerns about the focus on adoption to the exclusion of permanency. The question to be asking is not "how to develop a successful adoption system," but

rather, "how to develop a system that promotes permanency and stability in children's lives."

We recommend that the mission of the statewide system be broadened from "adoption" to "permanent family outcomes." Currently, the stated purpose of the proposed system is limited to adoption and the contracted services are confined to adoption related services (family recruitment, legal services, family resource development or home studies, placement services, post-adoption services, and competency-based and other training on adoption). A statewide system should be authorized and reimbursed for efforts to produce any of the permanency outcomes identified as goals in DPW regulations: return home; placement with relative; adoption; placement with legal guardian; independent living; and long-term placement in foster care. In order to insure that children most in need benefit from services, this system might be limited to children who have been in placement for two years or longer or those who have a goal of adoption (recognizing that despite this goal, adoption may not be practical or desirable).

According to some sources, the statewide adoption system will be expanded to include the full range of permanency options in future years. This would be consistent with our recommendation.

Recommendation 1.B. Family reunification, long-term foster care, and other permanent family outcomes should be reimbursed at the same level as adoption services.

While the increase in the state's reimbursement rate for adoption services to 100% is a positive step, this can result in inequities for many children if other services directed toward permanency by county or private agencies are not reimbursed at the

same rate. First, if family support services are reimbursed at a lower percentage than adoption services, this acts as an incentive for county agencies to initiate termination of parental rights and the recruitment of an adoptive family as opposed to family reunification. Second, children who cannot be reunited with their birth families, but who cannot be legally freed for adoption for whatever reason (e.g., judicial reluctance to terminate parent rights) still should have the opportunity to have a permanent home and family as children for whom adoptive families are sought. State policy and funding should support this. Third, as noted above, for some children, circumstances dictate against adoption and in favor of independent living, long-term foster care, or other permanent family options. Reimbursement rates should be tied to what is best in individual circumstances. We recommend, therefore, that services resulting in permanent family outcomes, including adoption, be reimbursed at 100% of cost. This recommendation does not include placement services that are not directed toward permanency.

Recommendation 1.C. Counties should focus not only on adoption, but other permanent family outcomes as well.

According to statewide groups and at least some county officials and associations, county children and youth services have adopted a crisis orientation as opposed to focusing on permanent options for children in their custody. According to the State Associations of County Commissioners and Children and Youth Administrators, one of the barriers to adoption is: "Adoption not a county priority given heavy demand on staff and resources for child protection and placement." County agencies seem to be devoting increased attention to adoption, but it is unclear whether they are devoting equal attention to other permanent outcomes. While many counties

contract with Project STAR for adoption services, none has contracted with the agency for services in support of other permanency options.

Under Pennsylvania's system, county agencies have the responsibility for fulfilling the permanency planning requirements of P.L. 96-272. These planning requirements should not be confused with the philosophy of permanency planning. In the first place, simply because an agency meets the planning requirements of P.L. 96-272 does not mean that it fulfills the philosophy underlying permanency planning. In the second place, county agencies have custody of children and, therefore, rightfully undertake the case plan and case review system requirements of P.L. 96-272, but this does not preclude contracting with private agencies to conduct permanency assessments or provide services designed to produce permanent family outcomes for children.

By recommending that county children and youth services agencies devote attention to the full range of permanent family options, including, but not limited to adoption, we are recommending that those county agencies that contract for adoption services also consider contracts for services for family reunification, long-term foster care, and other permanent options.

Mental Health/Mental Retardation Services

Traditionally, the concept of permanency planning has been foreign to the fields of mental health and developmental disabilities. Placements have been permanent only in the sense that once placed out-of-home children would never again experience a stable family and home life. Family reunification, adoption, and other permanent family relationships have not been options for children within mental health and developmental disability service systems.

Denied the opportunity to live with their birth families or other permanent homes, children in the mental health and mental retardation systems have existed in a kind of limbo. On the one hand, these systems have not adopted permanency planning as either a planning process or a philosophy. On the other hand, child welfare systems have not seen these children as their responsibility. Even when children in the mental retardation and mental health systems have been abandoned by their families, permanency planning has not been explored.

Pennsylvania's mental health and mental retardation agencies have devoted more attention to permanency planning than comparable agencies in the vast majority of states. As cited earlier, the Developmental Disability Planning Council has funded Project STAR's permanency planning efforts; the Office of Mental Retardation has included permanency planning in its Medicaid Waiver; and the CASSP program of the Office of Mental Health has adopted permanency planning as a goal.

The need for permanency planning for children in the mental health and mental retardation systems has been recognized by statewide evaluations of Pennsylvania's adoption system. Both the Education Law Center's 1987 report and the Legislative Budget and Finance Committee's evaluation recommended that permanency planning be incorporated into the mental retardation and mental health systems. In a response to the Legislative Committee's evaluation, the Secretary of DPW stated that the proposed statewide adoption system eventually will be expanded to include children in the mental health and mental retardation systems. DPW's "Request for Proposal for Pennsylvania Statewide Adoption System" includes a study of potentially adoptable children with mental retardation.

Pennsylvania's mental health and mental retardation systems should build on their efforts to date to extend the benefits of permanency planning to all children served within these systems. Specifically, this review addresses three issues: (1) state policy and regulations; (2) funding for permanency planning; and (3) large private ICFs/MR.

State Policy and Regulations

The realization of "Permanent Families: Permanent Homes" for children in the mental health and mental retardation systems will depend on fundamental changes in state policy and regulations regarding out-of-home placement. In the absence of these changes, a statewide adoption system or even permanency planning and adoption programs targeted toward these children will not have a major impact. Even with special funding for permanency planning, Project STAR has encountered formidable obstacles in attempting to bring permanency to the lives of children in the mental health and mental retardation systems. Permanency planning cannot be treated as a discrete program or add-on; it is a process and philosophy that must be built into the entire system.

Policy Issues. Let us explain why fundamental changes in policy and regulations are necessary. In the first place, especially in the mental health and mental retardation systems, permanency planning is most effective prior to out-of-home placement. Family preservation, with support services, is the first option, and family reunification is the second. In contrast to the child welfare system, most placements in the mental health and mental retardation systems are voluntary (although often due to lack of in-home supports); abuse and neglect are generally not factors. Once

families have voluntarily placed their children and have not been given an expectation of reunification, it can be difficult to restore the family ties.

In the second place, permanency planning cannot occur apart from agencies that serve or place children out-of-home. These agencies must be held accountable for permanency planning and be directly involved in the process. Project STAR's experience is instructive here. While Project STAR is willing and able to be involved in permanency planning with any child with a disability placed out-of-home, it does not have direct access to children placed in the mental retardation and mental health systems. Project STAR has worked hard to cultivate relations with ICFs/MR and residential facilities to identify children who can benefit from its permanency planning, but it is solely at the discretion of these facilities whether or not to refer children to the agency. If these facilities decide not to refer children to Project STAR, they are under no obligation or pressure to do so. Even children who have been abandoned by their families may not be referred to Project STAR. Since residential facilities are reimbursed according to the number of people served, they have a conflict of interest in regard to referring children to agencies like Project STAR.

In the third place, just as permanency planning requires access to children, it requires access to their families whether to encourage reunification or to explore other options. Few families of children in the mental health and mental retardation systems have had their parental rights terminated. Since families have not been charged with abuse or neglect, it is unlikely that judges will terminate their parental rights. As the Education Law Center pointed out in its 1987 report on permanency planning and adoption, judges might balk at adjudicating children as dependent and thus freeing them for adoption even in cases of abandonment. Because of the legal complexities

involved in placements in the mental health and mental retardation systems, permanency planning for many children in these systems requires the cooperation of families. They must voluntarily relinquish their parental rights. Agencies that place children have the closest contact with families and should be involved in these discussions with families.

In the fourth place, county children and youth services agencies have the discretion to accept custody for children served by the mental health and mental retardation systems. For children in mental health and mental retardation settings, children and youth services agencies are not required to assist in the terminating of parental rights or in facilitating adoption. The Education Law Center's 1987 report explained that under current laws and regulations, these agencies can simply refuse to accept children for service, unless ordered to do so by a court. Project STAR has already encountered resistance with one county children and youth services agency to assist in the termination of rights for the family of one child, even though the family is willing to relinquish these rights voluntarily.

Michigan's Example: Permanency Planning in Policy and Practice[2]. The State of Michigan stands alone in its commitment to permanency planning for children in the mental health and mental retardation systems. Pennsylvania may well be second to Michigan in attention devoted to permanency planning for these children, but the difference between these two states is that Michigan has translated its philosophical commitment into policies, procedures, and concrete initiatives.

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[2] We wish to express special thanks to Paul A. Newman, Director of Permanency Planning Program of the Michigan Department of Mental Health, for providing invaluable information on Michigan's permanency planning policies and program. Copies of Michigan's policies and descriptions of the Permanency Planning Program can be obtained through the Michigan Department of Mental Health, (Permanency Planning Program, Lewis Cass Building, Lansing, Michigan 48913)

Since 1983, Michigan's Department of Mental Health has operated a Permanency Planning Program for children with severe developmental disabilities. This program is described fully in the next section of this report. Just as important, Michigan has built permanency planning into its policies governing mental health and mental retardation services.

Like Pennsylvania, Michigan operates community mental health and mental retardation services through a county-based service system ("community mental health centers"), although in Macomb and Oakland counties in suburban Detroit both community mental health centers and the state-operated Macomb-Oakland Regional Center share responsibility for community services. Michigan's permanency planning policies are applicable to community services operated or contracted for by community mental health centers, state-operated facilities, and other specialized residential settings.

In Michigan, permanency planning is required through policies governing residential services, including the "Individual Plan of Service" and specialized foster care. The following are the most important features of Michigan's permanency planning policies.

First, for children and young adults, the Individual Plan of Service must include a written Permanency Plan. The Permanency Plan is defined as follows:

> PERMANENCY PLAN: means a plan designed to find and make secure a permanent family relationship, be it with the biological or extended family, adoptive family or foster family, in that order of preference.

The child's client services manager (case manager) has primary responsibility for the development of the permanency plan:

The client services manager is primarily responsible for the development of the permanency plan for each child and young adult in residential placement.

1. The permanency plan shall be developed in coordination with the child's parents, foster parents and referring social worker.

2. The priority permanency plan for each child whose parental rights are intact shall be to reunite the child with his/her biological or adoptive family, in the shortest possible time.

3. Adoption shall be the permanency of choice for those children who cannot return to their parent's care (or extended family), and whose parents, despite agency support and services, demonstrate an unwillingness or inability to resume custody of the child.

4. In those unusual circumstances where neither return home or adoption is considered to be an option, an alternative permanency shall be made for the child including but not limited to a permanent foster family agreement or arrangement. . .

The permanency plan must be "identifiable as distinct in the case record," must contain "goals, objectives, intervention strategies, and timetables for reaching the permanency goal," and must be reviewed every 90 days, including "a written assessment of progress in meeting the goals of the permanency plan." In addition, the permanency plan must be reviewed semi-annually by an administrative committee, which includes a permanency planning specialist and one person not directly responsible for services to the child, "to assure that a permanency plan is in place and to assist in the identification of barriers and facilitators to achieving the permanency goal."

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Second, Michigan's policies emphasize family reunification for children placed out-of-home and require planning for reunification prior to placement. Placement is not viewed as a terminal event, but a temporary arrangement in response to family crises or other extreme circumstances. Both the policy on the Individual Plan of Service and a policy on "Permanency Planning/Parent/Agency Agreements for Children with Developmental Disabilities" encourage family contact and visitation after placement and mandate an assessment of the parent or family needs to facilitate reunification.

Family reunification is favored over adoption. The policies read:

1) for children whose parent rights are intact, the permanency plan shall identify those conditions upon which the child will be returned home, the changes in parent and child's condition or conduct necessary for reunification and the services that will be provided to the family and child to facilitate reunification.

2) for children for whom adoption is the permanency plan of choice, the permanency plan shall identify the plan to free the child for adoption and secure an adoptive placement.

A standard "Parent/Agency Agreement" has been developed in Michigan to review progress made toward family reunification on a quarterly basis.

Finally, Michigan has developed a formal policy on "Permanent Foster Family Agreements" to facilitate permanency for children for whom family reunification and adoption are not options. As noted earlier, few families of children in the mental retardation and mental health systems have had their parental rights terminated. In contrast to the child welfare system, families have not been deemed abusive or neglectful. Further, out-of-home placement in the mental retardation and mental health systems has not been viewed as abandonment. With the possible exception of those

cases where parents have failed to maintain any form of contact and involvement with a child, it is unlikely that judges will terminate parental rights. For children of families who are unwilling or unable to accept their children home and will not voluntarily relinquish their parental rights, "permanent foster care" is likely to be the best option.

As described in Michigan's policy on Permanent Foster Family Agreements, this arrangement is intended to provide permanency for children when other options are not possible:

A. It is the responsibility of the Department of Mental Health to assure permanent family relationships for developmentally disabled children who are in mental health sponsored residential placements.

B. A Permanent Foster Family Agreement (PFFA) is designed as one alternative to increase permanency for some developmentally disabled children. A PFFA is not intended to replace the child's relationship with the biological parents and the birth family is expected to participate to the fullest extent possible in parenting the child when parental rights are intact.

C. A Permanent Foster Family Agreement shall be used only as a permanent placement for older youth for whom return home, securing voluntary relinquishment of parental rights, securing termination of parental rights, or placement for adoption is not a feasible plan.

D. A Permanent Foster Family Agreement shall be used only when a judgment is made that this is in the best interest of the child and that the child will receive the greatest degree of permanency through such an agreement than any other alternative placement.

E. A Permanent Foster Family Agreement shall be used only when the child continues to meet suitability for placement.

According to Michigan's policy, the Permanent Foster Family Agreement is a non-legal, good faith agreement between the provider agency, the foster parents, and a child's legal parents or guardian. The agreement is defined as follows:

> **PERMANENT FOSTER FAMILY AGREEMENT**: means a written document that is executed between the responsible mental health agency, the legal parents or guardian and foster parents that is designed to secure a permanent placement for the child. The agreement is not a legal document but represents a commitment by all parties (solely based upon the good will and good faith of the parties) toward making the contents of the agreement work. The agreement details the responsibilities of each party to the agreement including agency services, involvement of the parent or guardian with the child, and foster parent commitment to care for the child until adulthood.

The policy clearly states the criteria that must be met before a Permanent Foster Family Agreement can be considered as an option. One: the child must be at least 14 years of age; this option is not designed for young children who should live with the birth or adoptive parents. Two: the child has been in out-of-home placement for at least 18 months. Three: reunification with the child's family is not possible (e.g., 18 months of intensive services provided in accord with a parent/agency agreement have not resulted in reunification), and no other extended family member is willing and able to assume care for the child. Four: adoption is not the goal of choice because the child is not legally free for adoption and involuntary termination of parental rights is not feasible or because adoption is otherwise inappropriate and the child's parents have

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maintained an active relationship with the child. Five: an appropriate foster family is available, has maintained a positive ongoing relationship with the child, and is willing to make a long-term commitment to the child.

A standard Permanent Foster Family Agreement form has been developed. The agreement specifies the responsibilities of all parties: for the parents to maintain involvement with the child; for the foster parents to maintain their relationship with the child and to cooperate with the parents and support their regular contact with the child; for the agency to support the placement and to provide services as necessary. This agreement is signed by the parents, foster parents, and case manager and supervisor, and approved by the residential agency director and Permanency Planning Director.

Michigan's policies on permanency planning for children with developmental disabilities express a strong commitment to the philosophy of permanency and mandate specific planning processes and reviews. Of course, policies should be evaluated not according to whether they sound good on paper, but rather, in terms of their tangible results. The proof of the pudding is in the tasting. Judged from this perspective, Michigan's permanency planning efforts are impressive.

TABLE 3 summarizes the number of children with developmental disabilities in out-of-home placements in Michigan and the status of permanency planning efforts. As indicated in this table, Michigan has a small number of children placed out-of-home--256, with the vast majority of these (79.5%) in foster care; only 31 children remain in public and private institutions and only 23 are living in group homes. For these children, permanency goals are fairly evenly distributed among reunification

TABLE 3

THE MICHIGAN EXPERIENCE: PERMANENCY PLANNING IN POLICY AND PRACTICE

Children with Developmental Disabilities Out-of-Home 1991

NUMBER OF CHILDREN BY TYPE OF PLACEMENT	
Foster Care	202
Group Homes	23
State Facility	13
Nursing Home	10
Residential	8
	256

PERMANENCY PLANNING GOALS	
Family Reunification	49
Adoption	54
Permanent Foster Family	47
Transition to Adulthood	50
Other (Including Pending)	56
	256

PERMANENCY 1991

Family Reunification:	24
Adoption in Progress:	29

PERMANENCY PLANNING PROGRAM 1984 - 1991

Family Reunification:	134
Adoption:	62

with birth family, adoption, permanent foster care, and transition to adulthood or independent living (older children).

During Fiscal Year 1991, 24 children in Michigan were reunited with their families, and adoption proceedings were initiated for 29 children. Figures from 1984 to 1991 for the Permanency Planning Program demonstrate a major impact. In this period, 134 children have been reunited with their families and 62 have been placed in adoptive families. Given the barriers to adoption in the mental health and mental retardation systems, this latter figure is noteworthy. Beginning in Fiscal Year 1989, the Permanency Planning Program directed attention to family preservation and prevention of out-of-home placement. The Program's staff provides consultation to local providers and helps coordinate services and resolve conflicts between agencies to enable children to remain with their families. In 1991, 336 children benefitted from the Program's preservation/prevention services.

While policies, procedures, and practices developed in one state cannot always be transferred intact to another, Michigan represents a guiding model for any state committed to permanency planning for children in the mental health and mental retardation systems.

We offer the following policy recommendations for Pennsylvania's mental health and mental retardation systems.

Recommendation 2. Pennsylvania's Office of Mental Retardation and Office of Mental Health should formally incorporate permanency planning in their policies and regulations.

Since the permanency planning requirements of P.L. 96-272 only apply to children and youth services agencies, the Office of Mental Retardation and Office of

Mental Health should require permanency planning for children in their systems through state policies and regulations. While the planning and review requirements need not be as formal as those mandated by P.L. 96-272 (review by a court or administrative body), they should contain a clear mandate for the development of permanency plans for all children placed out-of-home and for periodic review.

Permanency planning policies and/or regulations, at a minimum, should address the following:

1. **A statement of philosophy and general policy**. This should be a clear statement that children belong in families and publicly supported services should be directed toward the following options, in order of preference: family preservation through support services; family reunification; adoption; permanent foster care; and transition to adulthood. Some of the guidelines developed by the Offices of Mental Health and Mental Retardation for specific programs (e.g., the Family Living Program Guidelines of the Office of Mental Retardation) already express this general philosophy. We are recommending that this philosophy underlie all services funded by these state offices.

2. **A requirement of the development of a written permanency plan for all children (ages 18 and under) in out-of-home placement**. This plan should be developed prior to placement and should contain: (a) a description of services provided to prevent placement and of the conditions necessitating placement; and (b) a statement of the permanency goal and the objectives, intervention strategies, and timetables to achieve this goal. As in the case of Michigan, the permanency plan might be included in the Individual Plan of Service.

3. **Guidelines for parent/agency agreements to facilitate reunification and for permanent foster care agreements for children for whom reunification and adoption are not feasible**. Michigan's guidelines on Parent/Agency agreements and Permanent Foster Care Agreements, described above, can serve as models. These guidelines might be incorporated into existing state program guidelines (e.g., Family Living Program Guidelines).

4. **A requirement for periodic review of permanency plans**. Michigan requires quarterly reviews of the progress in meeting permanency goals and a semi-annual review by an administrative committee, with representation by persons not directly involved in providing services to a child.

Recommendation 2.A. Pennsylvania's Office of Mental Health and Office of Mental Retardation should require an annual summary of permanency planning for all children placed out-of-home by county agencies.

As part of their Program Plans and Budget Requests, county mental retardation and mental health agencies should be required to provide the state offices with the following information: the number of children placed out-of-home by type of placement; the permanency goals for each of these children; and the progress made in meeting these permanency goals.

Recommendation 3. The Department of Public Welfare should clarify the responsibilities of county children and youth services agencies for children in the mental retardation and mental health systems who are candidates for adoption.

The Department of Public Welfare (DPW) operates both the Offices of Mental Retardation and Mental Health, on the one hand, and the Office of Children, Youth and

Families, on the other. Since county children and youth services agencies do not always accept responsibility for children in the mental retardation and mental health systems who are candidates for adoption (that is, those children who have been abandoned by their families or whose families are willing to voluntarily relinquish their parental rights), DPW should clarify the roles and responsibilities of these agencies regarding these children through regulations and/or interagency agreements.

We recommend that county children and youth services agencies be required to assume responsibility for coordinating the termination and voluntary relinquishment of parental rights for children in the mental health and mental retardation systems, that county mental health and mental retardation agencies reimburse them for these services, and that the State Offices of Mental Health and Mental Retardation, in turn, reimburse county mental health and mental retardation agencies. We are not recommending, however, that county children and youth services agencies take responsibility for permanency planning for children served by these systems; as recommended above, we believe that this responsibility should be assumed by mental health and mental retardation agencies.

Recommendation 4. County mental health and mental retardation agencies should adopt permanency planning policies and procedures.

With or without changes in state policies and regulations, county mental health and mental retardation agencies can implement permanency planning for all children under their care. As in the case of state policies and/or regulations, county policies should address: (1) a statement of philosophy on permanency planning; (2) a requirement of a written Permanency Plan for all children; (3) guidelines for Parent/Agency agreements and Permanent Foster Family agreements; and (4) a

requirement for periodic review of permanency plans. County mental health and mental retardation agencies might contract for technical assistance and specific permanency planning services from private agencies like Project STAR, although county agencies and service providers should be directly involved in the permanency planning process. Reimbursement for permanency planning services is currently available through the Office of Mental Retardation's Medicaid waiver program.

State Funding for Permanency Planning

In addition to policy changes recommended above, the realization of permanency for children in the mental health and mental retardation systems in Pennsylvania will require stable funding to support permanency planning. First of all, funding must be available for permanency planning or adoption services provided by or contracted for by county mental health and mental retardation agencies. The Office of Mental Retardation has taken positive steps to provide funding for these services through the Medicaid waiver.

Second, since most mental health and mental retardation agencies are unfamiliar with permanency planning philosophy and practices, they will require training and technical assistance on permanency planning as a philosophy and planning process. Before we offer recommendations on this need, let us review Michigan's Permanency Planning Program, which can serve as an example for any state's efforts.

Michigan's Permanency Planning Program is based in the state Department of Mental Health (which administers both mental health and developmental disability services) and is staffed by a director and four permanency planning consultants. The mission of the program is "to ensure that all children in the State of Michigan with special mental health needs have the benefit of permanent membership in a family

through the development of community care systems sufficient to sustain these children within their families." Michigan's Permanency Planning Program is involved in a range of activities to promote permanent family relationships for children. These include, among others:

1. **Monitoring out-of-home placements**. Program staff review placements and track the progress of permanency goals for children placed out-of-home.
2. **Consultation**. The Permanency Planning Program offers consultation to state and county agencies, hospitals, families and others on family preservation and other permanency goals. The program also helps coordinate services and resolve conflicts between different agencies.
3. **Training and technical assistance**. The program provides training on permanency planning values and practices and technical assistance to agencies and families.

Of course, the Permanency Planning Program also gives visibility to permanency planning and acts as an advocate for policies and programs directed toward permanency for children throughout the service system.

During its first five years, the Permanency Planning Program devoted most of its efforts to adoption and family reunification. Since 1989, the program has directed increased attention to family preservation and prevention of out-of-home placement.

In addition to the Permanency Planning Program, Michigan's Department of Mental Health contracts with a private agency for adoption services for children within its system. Other adoption or permanency planning efforts are funded by private grants, Developmental Disability Council grants, and other sources.

The realization of permanency for children in Pennsylvania's mental health and mental retardation systems will require financial support for permanency planning services, on the one hand, and training and technical assistance, on the other. We make the following recommendations.

Recommendation 5. The Office of Mental Health and Office of Mental Retardation should establish stable funding sources for permanency planning services.

County mental health and mental retardation agencies should receive federal or state funding for permanency planning services for all children served within their systems. Reimbursement should be available for the following services:

1. Permanency assessments of children placed out-of-home.
2. Family preservation services.
3. Family reunification planning and services.
4. Coordination of termination or voluntary relinquishment of parental rights with county children and youth services agencies.
5. Recruitment of foster families and coordination of permanent foster family agreements.
6. Adoption services not supported by other sources.
7. Postadoption services.

The Department of Public Welfare's "statewide adoption system" could potentially provide adoption services for children in the mental health and mental retardation systems. Since these children are not currently a priority of the proposed program, we recommend that the Offices of Mental Health and Mental Retardation

support these services until such time that the system is prepared to meet the needs of these children.

Counties could provide permanency planning services directly or contract with private agencies like Project STAR for these services. The Office of Mental Retardation's Medicaid waiver and targeted services management program are potential funding mechanisms for these services.

Recommendation 5.A. The Office of Mental Retardation should increase the visibility of Medicaid waiver funding for permanency planning.

The Office of Mental Retardation deserves recognition for its innovative use of the Medicaid waiver to fund permanency planning for children placed at ICFs/MR or at risk of placement. To date, counties have not used this opportunity to obtain Medicaid waiver funding for permanency planning services; only one or a handful of children have been served. There are many reasons for this: the relative newness of this waiver-funded option; the absence of policies requiring permanency planning; and the lack of county authority and responsibility regarding large private ICFs/MR. A major factor also seems to be county mental retardation agencies' lack of knowledge about permanency planning and the opportunities afforded by the waiver. Project STAR is currently providing permanency planning services to several children in the mental retardation system, but these services are funded solely through grants and not through the Medicaid waiver.

According to its Medicaid waiver submitted to the federal government, the Office of Mental Retardation plans to develop a Permanency Planning Training Manual. Along with other informational and training activities to increase awareness of

permanency planning and Medicaid waiver funding, the development of this manual should be a priority.

Since the design of Pennsylvania's Medicaid waiver for permanency planning is sound (with the exception of a limitation on post-placement services of one year), the Permanency Planning Training Manual can build on the list of services contained in the waiver:

Permanency Planning Services Consist Of

1. Identification of minor children in ICFs/MR, residential settings and birth families who are at risk of institutionalization and are lacking a permanent family relationship.
2. Assessment of children and their parents to determine the conditions, if any, under which reunification or permanency can occur.
3. Development of a permanency plan.
4. Identification and training of families.
5. Preparation of families and the child for permanency, including a home study.
6. Liaison with local agencies, school systems, and the adoption court.
7. Post family placement support for up to one year after the placement is finalized.

The manual should operationalize and expand upon this list of services. Special consideration should be given to the following issues. First, the manual should address the full range of permanency options: family preservation, family reunification, adoption, and permanent foster family arrangements. Family preservation, directed at children at risk of placement, should be stressed. Second, guidelines for the

development of permanency assessments and permanency plans should be provided. FIGURE 1, which summarizes Project STAR's adoption services, describes some of the elements of a Permanency Assessment. Michigan's policy on the Individual Plan of Service, discussed above, addresses important elements of a permanency plan. Third, building on Michigan's policies, the manual should provide guidelines and forms for Parent/Agency agreements in the case of out-of-home placement, and Permanent Foster Family Agreements. Fourth, guidelines in the manual should cover timetables and procedures for the periodic review of placements and progress in meeting permanency goals. Finally, the manual should address guidelines for working with children and youth services agencies and adoption agencies for children who are candidates for adoption.

Many existing resources can be used in the development of the manual. Project STAR has developed permanency planning procedures and training materials, and Michigan's Permanency Planning Program has developed a wealth of resources, guidelines, policies, and forms. Michigan's Department of Mental Health in cooperation with Spaulding for Children (1987) has produced a manual titled, Permanency planning practice for children with developmental disabilities within the Michigan mental health system: A manual for trainers.

Recommendation 5.B. The Office of Mental Retardation should seek additional funding for adoption and permanency planning for children in the mental retardation system or at risk of placement.

There is a pressing need for permanency planning services for children in Pennsylvania's mental retardation and mental health systems. Even if policies requiring permanency planning were implemented and Medicaid waiver funding for

permanency services fully utilized, county mental retardation agencies do not have the knowledge and capacity to provide permanency planning and the associated services without back-up and assistance. Further, the proposed "statewide adoption system" does not make children in the mental retardation and mental health systems a priority. As noted previously, this program will have a limited impact on children in these systems as long as it focuses exclusively on adoption as opposed to other permanency options.

The study of potentially adoptable children in mental retardation facilities contained in the Request for Proposal for a statewide adoption system may provide some useful information, but will not directly affect these children.

Recommendation 6. The Office of Mental Health and Office of Mental Retardation should provide or contract for centralized monitoring, consultation, and training and technical assistance on permanency planning for children served by their systems.

Michigan's impressive track record in permanency planning is directly attributable to its statewide Permanency Planning Program. As described above, this program has three major responsibilities:

1. Monitoring out-of-home placements. Reviewing placements and tracking the progress of permanency goals.

2. Consultation. Consultation to state and county agencies, hospitals, families and others on family preservation and other permanency goals; coordination of services; resolution of conflicts between different agencies.

3. Training and technical assistance. Training on permanency planning values and practices and technical assistance to agencies and families.

We recommend that Pennsylvania's Offices of Mental Health and Mental Retardation similarly sponsor centralized monitoring, consultation, and training and technical assistance on permanency planning. The Office of Mental Health's Child and Adolescent Services System Program (CASSP) is a possible vehicle to serve these purposes.

Large Private Residential Facilities

Throughout this policy review, we have referred to the "mental retardation system" and the "mental health system" in Pennsylvania. This is misleading. In both mental health and mental retardation, there exist at least three parallel service systems: state hospitals and centers; services operated or contracted for by counties; and large private residential facilities.

Most of the recommendations contained in this policy analysis would have an impact on children served under the auspices of county mental health and mental retardation agencies. Public and private institutions are another matter. Compared with most states, Pennsylvania has relatively few children in state centers and hospitals. The Office of Mental Retardation, in particular, stands out for its low rate of placement of children in state institutions (10 children). In memoranda to counties and regional MR program managers in 1988, OMR strongly discouraged placement in state centers through a protocol to prevent admission. Of course, children in state institutions should have the same permanency planning protections and services as children served by county agencies. State policies on permanency planning should apply to children in state centers and hospitals. Because of the small number of children in Pennsylvania's state centers, these institutions are not a major policy concern. Private residential facilities in Pennsylvania are more troublesome from the

vantage point of children placed there. As documented earlier, there were 387 children with developmental disabilities living in private ICFs/MR in Pennsylvania in 1991; admissions to these institutions during the 1990-91 Fiscal Year totalled 159.

Large (more than eight persons) private ICFs/MR in Pennsylvania seem to function as autonomous entities outside of the control of either county mental retardation agencies or the State Office of Mental Retardation. As long as they meet the ICF/MR standards, they play by their own rules. County mental retardation agencies are not responsible for placements at these facilities; nor does the State Office of Mental Retardation appear to control the flow of children into or out of these institutions.

The continued independence and autonomy of large private ICFs/MR in Pennsylvania will undermine other policies and programs designed to promote permanency for children with mental retardation. These facilities have a vested interest in opposing family reunification, adoption, and other permanency options. As Project STAR's experience suggests, private facilities may be reluctant to cooperate in pursuing adoption and other permanency options for children under their care.

Recommendation 7. County mental health and mental retardation agencies should be responsible for placements at large private residential facilities and for permanency planning for children placed at these facilities.

Whether this requires legal, regulatory, or policy changes, private residential facilities, and specifically large ICFs/MR, should be brought under the authority and responsibility of county mental health and mental retardation agencies. County agencies should serve as the "point of entry" into the private residential system and should assume responsibility for permanency planning for children at risk of placement

at these facilities or currently placed at them. The Offices of Mental Health and Mental Retardation should play leadership roles in advocating for the changes necessary for this to occur. As a long-term goal, we recommend that large private facilities be phased out completely.

CONCLUSION

This review started out as an evaluation of Project STAR. At Project STAR's request, the Center on Human Policy, through its federally funded Research and Training Center on Community Integration, agreed to review Project STAR's adoption and permanency planning program. Very early on in the evaluation, it became apparent that Project STAR is an exemplary agency and that the major issues confronting the agency were imposed by the policy context in which it operates. Of course, no agency is perfect. Like all agencies, Project STAR faces dilemmas and challenges in attempting to pursue its mission. We are providing suggestions for dealing with these dilemmas and challenges directly to Project STAR. Because the major issues confronting Project STAR in its mission as "permanency planning advocates" are outside of the agency's control, the focus of this report shifted to state and county policy in Pennsylvania. We agreed to provide Project STAR with a policy analysis on permanency planning for children with developmental disabilities in the Commonwealth.

The fact that the focus of this report was decided between Project STAR and the Center on Human Policy has one major advantage and one major disadvantage. On the one hand, The Center on Human policy is independent of any state or county agency in Pennsylvania and has not received funding from any source within the Commonwealth for this report. We have no stake in supporting any agency's agenda or priorities. On the other hand, we are in the position of offering our advice and recommendations to state and county agencies that did not request them.

Pennsylvania stands out from the vast majority of states in the large number of progressive leaders and organizations found there. Based on our experience in the

field of developmental disabilities, we are aware of the national reputations of individuals and agencies in the state. In the course of this review, we became aware of other organizations committed to the welfare of children in the children and youth services, mental health, and mental retardation systems. Let us single out some of these.

*The Pennsylvania Developmental Disabilities Planning Council is second to none in its commitment to and support of full community participation for adults and children with developmental disabilities.

*The Public Interest Law Center of Philadelphia and the Education Law Center are respected as two of the leading legal rights centers in the country.

*The Office of Mental Retardation has received recognition for its deinstitutionalization efforts and community initiatives.

*Many counties have strong leadership or have supported innovative efforts. In Allegheny County, the office of the Chairman of the County Commissioners has been a strong advocate for Project STAR; in Philadelphia, the recently appointed director of the mental health/mental retardation agency holds great promise as a progressive leader in the field; Northumberland County is widely respected for its mental health and mental retardation services.

*Ever since the famous PARC v. Commonwealth of Pennsylvania case, the Pennsylvania Association for Retarded Citizens has been respected nationally for its strong advocacy on behalf of people with mental retardation. Other groups, such as the Parents Involved Network, are also strong advocates within the Commonwealth.

*Organizations and agencies outside of the fields of mental health and developmental disabilities--including the Permanency Planning Task Force, the Legislative Budget and Finance Committee, the Pennsylvania Council of Children's Services, and DPW's Office of Policy, Evaluation and Development--have devoted uncommon attention to children with developmental and mental disabilities.

It is because of the reputations of these organizations and groups and their commitment to the welfare of children with disabilities that we are hopeful that the recommendations contained in this report will receive widespread attention and careful consideration.

ADDITIONAL REFERENCES

Center on Human Policy. (1987). Families for all children. Syracuse, NY: Author.

Taylor, S. J., Lakin, K. C., & Hill, B. K. (1981) Permanency planning for children and youth: Out-of-home placement decisions. Exceptional Children, 55(6), 541-549.

APPENDIX: METHODOLOGY

This policy analysis and evaluation of Project STAR and permanency planning in Pennsylvania was conducted between March, 1991 and March, 1992.

The analysis is based on the following sources of information: (1) three site visits to Allegheny and Beaver Counties; (2) a site visit to Harrisburg; (3) additional phone interviews; (4) a family mail/phone survey; (5) Project STAR grant proposals, reports, policies and procedures, training materials, and other information; and (6) policy reports, policies, program descriptions, and other public information on Pennsylvania's mental retardation, mental health, and children and youth services systems.

Site Visits to Allegheny and Beaver Counties. Visits were made to Allegheny and Beaver Counties in March, July, and September, 1991 by three separate researchers. During these visits, the following interviews and observations were conducted:

*Eight interviews with Project STAR staff, in addition to extensive discussions with the Director.

*A meeting with Allegheny County representatives, including Chairman Tom Foerster's Office, the Children and Youth Services agency, and the Mental Health/Mental Retardation/Drug and Alcohol Program.

*Visits to nine families served by Project STAR; in the majority of these visits, Project STAR staff were not present.

*Site Visit to Harrisburg. A two-day visit was made to Harrisburg in October, 1991 to meet with representatives of state and private agencies and

organizations. Interviews were conducted with representatives of the following agencies:

*The Office of Mental Retardation

*The Office of Mental Health

*The Office of Children, Youth and Families

*The Office of Policy, Evaluation and Development

*The Developmental Disabilities Planning Council

*The Pennsylvania Council of Children's Services

Additional Phone Interviews. In addition to on-site meetings and interviews, phone interviews were conducted with six additional public or private agency representatives knowledgeable about Project STAR or permanency planning in Pennsylvania.

Family Mail/Phone Survey. Project STAR sent a letter to adoptive families requesting their cooperation with this policy analysis and evaluation. Families were asked to consent to having their names forwarded to the Center on Human Policy; those providing consent were asked their preference on responding to a phone or mail survey. Eleven families responded to a structured mail/phone survey on their evaluations of Project STAR and experiences with the adoption process and other agencies.

Project STAR Materials. This review included an exhaustive review of non-confidential Project STAR materials and documents:

*Eleven grant proposals submitted by Project STAR to federal, state, and private sources as well as project progress reports submitted to funders.

*Project STAR's Permanency Assessment procedures, Purchase of Service Contract policy, and other policies and procedures.

*Informational and training materials for families.

*Summary information and data on adoptions and permanency planning services.

Policy Reports and Documents. A final source of information for this review consisted of policy reports and evaluations, laws, regulations, policies, program descriptions, and other documents relating to Pennsylvania's mental retardation, mental health, and children and youth services systems. These included:

*Developmental Disability Planning Council funded reports and evaluations conducted by the Human Service Research Institute (1991), Spaulding for Children, National Resource Center for Special Needs Adoption (1989), and the Education Law Center, Inc. (1987).

*The Legislative Budget and Finance Committee's 1991 report, Evaluation of Adoption Processes for Children with Special Needs, including appended materials on the Permanency Planning Task Force, the Department of Public Welfare's positions and proposals, and position statements of the Pennsylvania State Association of County Commissioners and Pennsylvania Children and Youth Administrators.

*Laws, regulations, and policies on Pennsylvania's Mental Retardation and Children and Youth Services systems.

*The Office of Mental Retardation's 2176 Medicaid Waiver materials.

*Statistics, budget documents, and program descriptions from the Office of Mental Retardation.

*Reports and funding priorities from the Developmental Disabilities Planning Council.

In addition to information on Project STAR and Pennsylvania's mental retardation, mental health, and children and youth services systems, this report builds on the Center on Human Policy's ongoing studies of the "state of the art" in community integration for adults and children with developmental disabilities.

ACKNOWLEDGEMENTS

We wish to thank all of the public officials and public and private agency representatives who cooperated with this policy analysis and evaluation and provided information on Project STAR and state and county policy in Pennsylvania: Robert Nelkin, Victor Papale, Raymond Firth, Dana Olsen, Mel Knowlton, David B. Schwartz, Rosemary Barrett, Ed Spreha, Connie Delmuth, John Pierce, Robert Gioffre, Bill Christner, and A.J. Hildebrand. We also express special thanks to Susan Maczka and the staff of Project STAR and the many families who shared their experiences with us. Finally, we thank Paul A.Newman of the Michigan Department of Mental Health for information on that state's permanency planning efforts. We also want to express our appreciation of Debbie Simms, Rachael Zubal, Cyndy Colavita, Rannveig Traustadottir, and Susan O'Connor of the Center on Human Policy for their support of this report.

EXECUTIVE SUMMARY

PERMANENCY PLANNING FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES IN PENNSYLVANIA: THE LESSONS OF PROJECT STAR

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Viewed in the context of current trends, Project STAR stands at the forefront of efforts to insure children's right to permanent and stable family relationships. Project STAR has demonstrated that children with a range of disabilities can be supported in their birth families or placed in adoptive families.

In this report, we examine the experience of Project STAR for the lessons for state and county policy toward children with developmental and other disabilities in Pennsylvania. The report is divided into three major parts. Part I reviews the history and experience of Project STAR itself. Part II examines the policy context in which Project STAR operates. Part III addresses policy issues that impact on Project STAR's mission and contains policy recommendations based on this review.

PART I. PROJECT STAR:

FROM ADOPTION TO PERMANENCY PLANNING

Project STAR was established in 1985 with funding from the Pennsylvania Developmental Disabilities Planning Council (DDPC) as a collaborative project of the Rehabilitation Institute of Pittsburgh, the Allegheny County Children and Youth Services agency, and Three Rivers Adoption Council (TRAC). Since 1988, when this three-year funding from DDPC ended, Project STAR has been funded through a patchwork of grants, contracts, and other sources.

Mission of Project STAR

Consistent with its initial funding from DDPC, Project STAR was founded as an adoption agency for children with developmental disabilities. Beginning in 1989, Project STAR's mission gradually broadened to focus on permanency planning for children with disabilities.

Permanency planning is both a planning process and philosophy directed toward ensuring each child's rights to a permanent home and stable relationships with one or more adults. According to the philosophy of permanency planning, children belong in families and need permanent family relationships. Permanency planning emphasizes supports to families to enable them to care for their children, family reunification when children have been placed out-of-home, and adoption or other permanent family placements for children who cannot live with their birth families.

In child welfare, or children and youth services, permanency planning is required by the federal Adoption Assistance and Child Welfare Act of 1980, P.L. 96-272. Few mental retardation, developmental disability, or other disability agencies in the United States have incorporated permanency planning into their policies and procedures.

Project STAR: Adoption

Project STAR has been extremely successful in arranging adoptions and has demonstrated that caring and loving adoptive families can be found for children who have been considered "unadoptable" because of their disabilities.

Project STAR: Permanency Planning

The agency's permanency planning activities fall into four categories. The first is "family preservation" or efforts to prevent out-of-home placement. The second category of permanency planning activities relates to encouraging a family's involvement with their children who have been placed out-of-home. The third category is "family reunification." The final category of Project STAR's permanency planning activities relates to finding other permanent options for children who cannot or should not be reunited with their families.

PART II. THE POLICY CONTEXT

CYS Versus MH/MR Services

Like many states, Pennsylvania supports both "generic" children and youth services and "categorical" mental health/mental retardation services. Children with emotional disturbance, mental retardation, or developmental disabilities may be placed out-of-home either through children and youth services or mental health/mental retardation agencies.

In contrast to children and youth service agencies, Pennsylvania mental health/mental retardation agencies traditionally have not been involved in permanency planning and adoption. The DPW's Office of Mental Health (OMH) and Office of Mental Retardation (OMR) have begun to devote attention to permanency planning and adoption.

According to OMR documents, in 1991, there were 707 children with mental retardation under the age of 18 living in mental retardation facilities and other out-of-home placements. These included 387 children in Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), 310 children in licensed community and family homes, and 10 children in state centers or MR units.

State Versus County

In both children and youth services and mental health/mental retardation services, Pennsylvania ostensibly supports a county-based service system. The DPW funds and regulates services; county children and youth service agencies and mental health/mental retardation agencies provide or arrange for services. Of course, Pennsylvania continues to operate state centers or institutions, directly. These centers remain outside of county control. To the credit of the OMR, only 10 children under 18 years of age live at state centers or MR units.

While Pennsylvania has adopted a county-based service system for children and youth services and mental health/mental retardation services, large private ICFs/MR operate independently of county mental health/mental retardation agencies.

Strengths

Pennsylvania will never develop a perfect children and youth services or mental health/mental retardation services system; no state will. In attempting to enhance permanency for children with disabilities, leaders in Pennsylvania should recognize and build on their strengths. In the course of this review, several strengths became apparent.

PART III. POLICY ISSUES AND RECOMMENDATIONS

This report specifically examines the policy issues that impact on Project STAR's adoption and permanency planning mission for children with developmental disabilities. Of course, Project STAR's mission is affected by issues confronting special needs adoption and developmental disability services in general.

While this policy review did not look in depth at all of these issues, our findings are consistent with many of those contained in previous evaluations of adoption, permanency planning, and family support services in Pennsylvania.

1. **Pennsylvania needs a stable funding source for flexible and individualized family support services for families of children with disabilities.**

2. **For children in the custody of children and youth services agencies, increased attention must be devoted to adoption and permanency planning.**

3. **Adoption assistance subsidies are inadequate and provided in an inequitable manner.**

4. **Post-adoption services are inadequate.**

Children and Youth Services

"Special needs adoption," including adoption for children with mental or developmental disabilities, has received considerable attention in Pennsylvania. While increased attention focused on adoption of children with special needs in Pennsylvania is necessary and commendable, adoption should not be considered apart from the broader issue of permanency for children in the custody of children and youth service agencies. Adoption is only one permanency option, and an over-emphasis on adoption to the exclusion of other options will not serve the interests of many children in the CYS system.

Recommendation 1. Reform proposals for Pennsylvania's children and youth services should address permanency for children with disabilities as opposed to an exclusive emphasis on adoption.

Recommendation 1.A Any statewide system should support the creation of permanent family outcomes for children and not adoption as the single option.

Recommendation 1.B Family reunification, long-term foster care, and other permanent family outcomes should be reimbursed at the same level as adoption services.

Recommendation 1.C Counties should focus not only on adoption, but other permanent family outcomes as well.

Mental Health/Mental Retardation Services

Pennsylvania's mental health and mental retardation systems should build on their efforts to date to extend the benefits of permanency planning to all children served within these systems. Specifically, this review addressed three issues: (1) state policy and

regulations; (2) funding for permanency planning; and (3) private residential facilities and ICFs/MR.

State Policy and Regulations

The realization of "Permanent Families: Permanent Homes" for children in the mental health and mental retardation systems will depend on fundamental changes in state policy and regulations regarding out-of-home placement. In the absence of these changes, a statewide adoption system or even permanency planning and adoption programs targeted toward these children will not have a major impact. Permanency planning cannot be treated as a discrete program or add-on; it is a process and philosophy that must be built into the entire system.

The State of Michigan stands alone in its commitment to permanency planning for children in the mental health and mental retardation systems. Pennsylvania may well be second to Michigan in attention devoted to permanency planning for these children, but the difference between these two states is that Michigan has translated its philosophical commitment into policies, procedures, and concrete initiatives.

While policies, procedures, and practices developed in one state cannot always be transferred intact to another, Michigan represents a guiding model for any state committed to permanency planning for children in the mental health and mental retardation systems.

Recommendation 2. Pennsylvania's Office of Mental Retardation and Office of Mental Health should formally incorporate permanency planning in their policies and regulations.

Recommendation 2.A. Pennsylvania's Office of Mental Health and Office of Mental Retardation should require an annual summary of permanency planning for all children placed out-of-home by county agencies.

Recommendation 3. The Department of Public Welfare should clarify the responsibilities of county children and youth services agencies for children in the mental retardation and mental health systems who are candidates for adoption.

Recommendation 4. County mental health and mental retardation agencies should adopt permanency planning policies and procedures.

State Funding for Permanency Planning

The realization of permanency for children in Pennsylvania's mental health and mental retardation systems will require financial support for permanency planning services, on the one hand, and training and technical assistance, on the other.

Recommendation 5. The office of Mental Health and Office of Mental Retardation should establish stable funding sources for permanency planning services.

The DPW's "statewide adoption system" could potentially provide adoption services for children in the mental health and mental retardation systems. Since these children are not currently a priority of the proposed program, we recommend that the OMH and OMR support these services until such time that the system is prepared to meet the needs of these children.

Recommendation 5.A. The Office of Mental Retardation should increase the visibility of Medicaid waiver funding for permanency planning.

Recommendation 5.B. The Office of Mental Retardation should seek additional funding for adoption and permanency planning for children in the mental retardation system or at risk of placement.

Recommendation 6. The Office of Mental Health and Office of Mental Retardation should provide or contract for centralized monitoring, consultation, and training and technical assistance on permanency planning for children served by their systems.

Large Private Residential Facilities

Throughout this policy review, we have referred to the "mental retardation system" and the "mental health system" in Pennsylvania. This is misleading. In both mental health and mental retardation, there exist a least three parallel service systems: state hospitals and centers; services operated or contracted for by counties; and private residential facilities.

Large private ICFs/MR in Pennsylvania seem to function as autonomous entities outside of the control of either county mental retardation agencies or the State OMR. The continued independence and autonomy of large private residential facilities in Pennsylvania will undermine other policies and programs designed to promote permanency for children with mental retardation and developmental disabilities.

Recommendation 7. County mental health and mental retardation agencies should be responsible for placements at large private residential facilities and for permanency planning for children placed at these facilities.

Preparation of this report was supported by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education for the Research and Training Center on Community Integration through Cooperative Agreement #H133B00003-90 awarded to the Center on Human Policy at Syracuse University. The opinions expressed herein are solely those of the authors and no endorsement by the U.S. Department of Education should be inferred.

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